Promoting the Well-Being of People with Neurodevelopmental Disabilities through TRAUMA-INFORMED SUPPORTS

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PROMOTING SELF-DETERMINATION, SUPPORTING MENTAL HEALTH, HEALING TRAUMA.

Issue Statement

Minnesota must take an honest look at the widespread practice of managing the behavior of people with neurodevelopmental and other disabilities (NDD) through Applied Behavior Analysis (ABA). This approach fails to honor the unique qualities, ways of knowing, lived experiences, and self-determination of people with NDD. Even though Minnesota aims to provide positive behavioral supports, the focus is still on *changing* the person who is *misbehaving*. Neuroscience is changing our understanding of behavior, including how distress, fear, and trauma are expressed. Minnesota must stop using harmful behavior management practices, admit the pain it has caused, and invest in a trauma-informed system of services and supports that promotes the human rights, well-being, healing, and self-determination of children and adults with neurodevelopmental disabilities.

Disclaimer: This policy advocacy brief is written using a disability justice perspective and using both identity first and person first language to reflect the differing preferences and ways disabled people identify themselves.

Understanding the Problem

"ABA punishes people for expressing their natural instincts, often survival instincts, and not only disregards the impact of past trauma, but can create ongoing complex trauma".[1]

People with neurodevelopmental disabilities, including people with intellectual and developmental disabilities (IDD) and autistic people (Autism Spectrum Disorder - ASD), are routinely subjected to behavior management using Applied Behavior Analysis (ABA). ABA was developed from the School of Behaviorism which aimed to change undesirable behavior using operant conditioning—positive and negative reinforcement or punishment to change undesirable behavior. ABA uses functional assessments to determine the motivation (purpose) of *undesirable* behavior to develop interventions aimed at producing more *socially acceptable* behavior.

Minnesota widely practices a form of behaviorism called Positive Behavior Supports (PBS). PBS was developed in 1990 as an alternative to aversive behavior management. It has taken on different forms but continues to reinforce behavior change of disabled people though *rewards for acceptable* behavior (positive reinforcement). Although PBS's commitment to respect for the individual, meaningful outcomes, social validation, dignity, normalization, inclusion, person-centeredness, self-determination, and stakeholder participation are an improvement from past forms of behaviorism, **IT IS STILL HARMFUL**. Two practices that can traumatize and re-traumatize people who experience them; manual restraint and seclusion, while restricted are still allowed in Minnesota.

Kendra's Story of Behavior Mismanagement

Kendra's story represents the lived experience of many people with NDD who are given a positive behavioral support plan to *change* or *manage* their behavior.

Kendra is a spunky 25-year-old young woman who lives in a medium size town in South-Central Minnesota. Kendra has been through a lot in her life. She is not close with her family and does not have close friends. She does not talk about it, but Kendra is a victim/survivor of sexual abuse. She was abused by her adoptive father. When she told her adoptive mother about the abuse, she did not believe her. Now, Kendra does not stand up for herself, she is haunted by flashbacks and has feelings of shame and guilt. Kendra has no one she trusts to turn to, so she cuts to numb the pain. Because of her *behaviors*, she has moved frequently and is reminded that she does not belong or fit in anywhere. Although she loves drawing, listening to music, and watching movies, she does not often get to do these things that she enjoys. Why? Because Kendra, who has a neurodevelopmental disability, lives in a group home where the *function* of her *behaviors* are misunderstood and misdiagnosed. Her failure to comply with her behavior support plan led to her privileges being revoked — meaning she is denied the opportunity to do the things she enjoys most in life.

Kendra's behavior support plan rewarded her with her favorite things on days she did not have a *behavior*. Her support staff are allowed to manually restrain Kendra when she has an outburst, cutting herself, or is physically aggressive and does not respond to *less restrictive measures*. When she is manually restrained Kendra feels scared, trapped, misunderstood, and fights back to gain control. Despite her behavior support plan, Kendra continues to engage in self-harm and other *unwanted behaviors.*

The Limitations of a Behavioral Approach

"[People with NDD] continue to be regarded and treated by professionals as though advances in the last 30 years had never occurred".[1]

While most of adult psychology has moved away from behaviorism, it is still widely used with adults with NDD. People with NDD are infantilized and have been viewed as less than human for centuries. ABA is so embedded in our systems that we fail to recognize the harm it causes.

- Behavior plans prioritize the comfort of nondisabled individuals by enforcing neurotypical and *normal* behavior leading to denial of one's true self, shame, masking, and mental health challenges for disabled people.
- When compared to nondisabled people, people with disabilities are 4 times more likely to be victims of crime and people with ID have a 7 times higher rate of sexual assault. ABA puts people at greater risk for abuse by training them to be compliant.
- Behaviorism undermines happiness and a unique sense of identity, the strongest drivers of internal motivation and change.[1]
- Self-advocates' report ABA has harmed them. Yet, they are ignored in favor of the antiquated practice of behaviorism.
- ABA fails to recognize when *unwanted behavior* is a safety response (fight or flight) and the trauma and stressful life events routinely experience by people with NDD.[1]

In order for people with NDD to receive actual person-centered supports, mental health supports that promote wellness and healing, and experience true self-determination, our reliance on behaviorism, even positive behavior supports, must stop.

The Current Policy Approach in Minnesota: Positive Behavioral Supports

Minnesota has made strides in moving away from punitive behavior management to positive behavioral support for children and adults receiving Department of Human Services (DHS) licensed-services.

- **Jensen Settlement Agreement.** The 2011 Jensen Settlement Agreement was a catalyst for change. The Agreement is the result of a lawsuit filed against DHS alleging the former Minnesota Extended Treatment Options (METO) program used seclusion and restraint in a way that broke the law and violated the rights of people with disabilities.
- **245D**. Minnesota's revised standards overseeing DHS services (245D / 245A), included restricting the use of aversive & deprivation procedures for behavior management.
- **Olmstead Plan**. As part of the Jensen Settlement Agreement, Minnesota developed an Olmstead Plan to ensure "people with disabilities are living, learning, working, and enjoying life in the most integrated setting." The plan has positive support goals to "increase the use of positive supports, so that fewer people with disabilities need to be physically restrained to keep them safe in an emergency, no matter whether it's where they live, work, or go to school."
- **Positive Support Rule**. On August 15, 2015, Minnesota created a new rule governing positive-support strategies and restrictive interventions called the "positive supports rule."

These measures are a step in the right direction. They are not enough. Minnesota's emphasis on *supporting the behavior* of children and adults with neurodevelopmental disabilities is still focused on assessing, managing, and changing their behavior.

Investing in a New Direction: A Trauma-Informed Approach

ABA fails to acknowledge *unwanted behavior* as a trauma response.[1]

Research by leading trauma expert, Bessel van der Kolk, shows that traumatic life experiences can have a big impact on how people experience the world around them and react to stressors in their lives. People with NDD experience a higher rate of traumatizing events than nondisabled people. Despite showing signs of trauma, people with NDD are less likely to be diagnosed with PTSD. In part because it can be difficult to diagnose in people with NDD, but also because of a failure to imagine that the *unwanted behavior* could be a trauma response.

Experts like Karyn Harvey, Clinical and Applied Developmental Psychologist, created tools[1,2] to recognize trauma and PTSD in people with NDD. She has also developed approaches to intervene that support wellness and healing. DHS has contracted with Dr. Harvey to educate service providers on how to *reframe behavior* and provide trauma-informed supports. This is a good start. The whole system needs to become trauma-informed.

- Mental health and disability services (including education, case management, home, work), particularly for people with NDD, have traditionally been provided through separate and parallel systems of care —a siloed approach. People with NDD need the two systems, and everyone working in them, to collaborate and provide trauma-informed supports.
- Trauma-informed behavior support plans still run the risk of focusing on *behavior*. **Mental health support plans**[1] focus on promoting mental health wellness and healing, emphasize positive identity development, and include a happiness assessment to shift the focus of supports away from changing *behavior* to investing in what makes people happy and helps them live their best lives.

Revisit Kendra's Story: A Trauma Informed Approach

Imagine if Kendra had a Mental Health Plan that addressed her past traumatic experiences and prioritized her happiness. Talking with a trusted counselor each week is helping her recover from the impact her past trauma and support healing. Now, when Kendra gets the urge to cut, she draws on her arm instead. She is supported in moving to a different part of town without so many bad memories. Her staff listen to her and she trusts them. When they notice Kendra is having a bad day, they focus on how they can help, offering to play her favorite music. Kendra dances and moves her body. Slowly, but surely, scary feelings pass. Now that Kendra feels safe and is in the process of healing, she is more confident and surer of herself. Although she still struggles, Kendra is happier and is on her way to living her best life.

Policy Position Statement

Even though Minnesota aims to provide positive behavioral supports, the focus is still on *changing* the person who is *misbehaving*. This approach fails to honor the unique qualities, ways of knowing, lived experiences, and self-determination of Minnesotans with neurodevelopmental disabilities. Minnesota must stop using harmful behavior management practices, admit the pain it has caused, and invest in a trauma-informed system of services and supports that promotes the human rights, well-being, healing, and self-determination of children and adults with neurodevelopmental disabilities.

For these reasons we recommend **INVESTING IN A TRAUMA INFORMED SYSTEM OF SUPPORTS AND SERVICES LED BY PEOPLE WITH NEURODEVELOPMENTAL DISABILITIES.**

- **Form a state-wide task force** to evaluate the system. The task force will: 1) Take a closer look at our current approaches and see what regulations are not compatible with a trauma informed approach. 2) Create a plan to get disability services caught up to the standard of care currently used in mental health. 3) Implement the system change. 4) Hold the state accountable.
- **Immediately direct money into a trauma informed approach** that is holistic and supportive. Require trauma informed training for licensed professionals currently involved in the development of support plans for children and adults with NDD.
- **Stop using positive behavior support plans** and focusing on behavior. Transition to providing support through Mental Health Plans that assess for trauma and happiness.
- **Create a robust network** of culturally diverse and culturally responsive mental health professionals trained and confident in providing trauma informed care for people with NDD.

References

Full text online sources were used to create this policy advocacy brief and are linked throughout the document.

[1]Harvey, K. (2012). *Trauma-informed behavioral interventions: What works and what doesn't*. American Association on Intellectual and Developmental Disabilities.

[2]Marcal, S. & Trifoso, S. (2017). *A trauma-informed toolkit for providers in the field of Intellectual & Developmental Disabilities*. Center for Disability Services.

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